



The University of Manchester

IN-CITU: Interactions between Cognitive Impairment & Transport in Urban Environments

You are being invited to take part in a research study of public transport use by people with dementia. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully before deciding whether to take part, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Thank you for taking the time to read this.

➤ **Who will conduct the research?**

Dr James Rupert Fletcher, School of Social Sciences, University of Manchester.

➤ **What is the purpose of the research?**

The aim of this study is to investigate people with dementia's experiences of public transport in Greater Manchester. Local government wants to make public transport easier to use for people with dementia. There is a lack of research into how people with dementia experience public transport. This study is trying to change this.

➤ **Am I suitable to take part?**

We are invited people who have been diagnosed with dementia and use public transport in Greater Manchester.

➤ **Will the outcomes of the research be published?**

The results of the study will be represented online, in scientific journals and conference presentations. Photos and videos from the research will be displayed in an exhibition across local public transport. It is your decision whether you would like photos and videos from your journey to be included.

➤ **Disclosure and Barring Service (DBS) Check**

The researcher has undergone an Enhanced Disclosure and Barring Service (DBS) check.

➤ **Who has reviewed the research project?**

NHS REC [reference 22/NW/0142].

➤ **Who is funding the research project?**

The Wellcome Trust

➤ **What would I be asked to do if I took part?**

At a time of your choosing, a researcher will visit you at home or another place of your choosing. The researcher will check that you understand what the study is about and what taking part involves. A family member or friend of your choosing should be present. The researcher will then arrange to accompany you on a journey using public transport. A family member or friend can come with us if you would like. This can be any journey that you would normally make, to any location using any type of public transport. With your permission, the researcher will record your conversation, take photographs and record video during the journey. You can also take photographs and record video if you want to. You can choose to be accompanied on between one and five journeys. Participation should not lead to any unusual risks or benefits.

➤ **Will I be compensated for taking part?**

We are not offering any payment for participation.

➤ **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further. You are free to decline the recording and can stop recording at any time.

➤ **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically, we will need to collect your name and contact details, consent recordings, voice recordings, journey routes and photos/videos of your journey which may include you.

➤ **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

➤ **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings or photographs. If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#):

<https://documents.manchester.ac.uk/display.aspx?DocID=37095>. Sometimes your rights may be limited if it would prevent or delay the research. If this happens you will be informed by the research team. If you would like more general information on how

researchers use data about patients, please visit: www.hra.nhs.uk/information-about-patients/

➤ **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way. Participants will be assigned an ID number only known to the research team and a key will enable the researcher to identify participants. This key will be destroyed at the end of the project (August 2024). Data will be securely stored at the University of Manchester until August 2024, when it will be permanently archived in a data repository so that future researchers can use it. Audio recordings will be transcribed by the researcher and all identifiable information will be removed. Visual media will not be altered to remove personal information as this will be used in a public exhibition with your consent. If you consent to your media being included in the exhibition, it will be shared with Transport for Greater Manchester.

At the end of the project, we will deposit the dataset in an open data repository where it will be permanently stored. We will use 'ReShare'. Researchers at other institutions and others can access the data directly from the repository and use it for further research or to check our analysis and results.

Consent forms will be kept for the duration of the project. These will be stored in a locked cabinet, to which only James Fletcher will have access. Consent forms will be destroyed 5 years after the end of the project (August 2029) in line with The University of Manchester's Information Governance Office Records Retention Schedule.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant. Interview location details will be left in a sealed envelope with a member of the research team during the interview to ensure researcher safety. The envelope will be destroyed following the interview.

If, during the study, we have concerns about your safety or the safety of others, we will inform relevant authorities in line with government guidance.

➤ **Harm**

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In the unlikely event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

➤ **Additional Covid Information**

Are there any additional considerations that I need to know about before deciding whether I should take part?

Participation should not entail any additional risk of contracting Covid-19 because the journeys involved are normally undertaken irrespective of research.

What additional steps will you take to keep me safe while I take part?

The researcher will be tested before each journey. Research equipment will be disinfected and PPE will be worn in confined spaces.

Is there any additional information that I need to know?

All research activities will comply with public health guidance at the time. If the guidance changes, the research activities will be adjusted accordingly and you will be informed.

➤ **Contact details for complaints**

If you have a complaint that you wish to direct to members of the research team, please contact James:

EMAIL: JAMES.FLETCHER@MANCHESTER.AC.UK

PHONE: 07477663026

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

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If you have any queries about the study or if you are interested in taking part then please contact James:

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